The Case for Worker Notification

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In the late summer of 1981 the national news media reported a story that was referred to in the most extreme form by the tabloid *Weekly World News* as "Cancergate."[1] The federal government, notably the National Institute for Occupational Safety and Health (NIOSH), had conducted studies on large groups of workers in which serious disease risks had been found. The problem was that the government had not informed the subjects in those studies of their adverse health risks.

Although these issues had been debated in policy terms for a half decade before 1981,[2] they became known widely when the Workers' Institute for Safety and Health (WISH) and NIOSH launched three intervention projects to demonstrate the feasibility of notifying and offering medical and related assistance to members of occupational high-risk groups. Those projects were conducted between 1980 and 1983. Since then, legislation has been introduced in Congress. The High Risk Occupational Disease Notification and Prevention Bill was passed by the House of Representatives on October 15, 1987, but was withdrawn after a lengthy filibuster in the Senate. The legislation was reintroduced in the 101st Congress in 1989. This legislation has been opposed strongly by the executive branch of the federal government. Since 1983, no new efforts have been made to notify occupational high-risk groups. Within the U.S. Public Health Service these efforts have been neglected with vigor.[3]

DEMONSTRATION PROJECTS

The three demonstration intervention projects conducted are summarized comparatively in TABLE 1. These projects have been discussed in detail elsewhere.[4] Their key characteristics are as follows:

Augusta Chemical Company. The first notification involved predominantly black male workers who between the 1940s and 1972 were exposed to betanaphthylamine at the Augusta Chemical Company, Augusta, Georgia. These workers were unskilled, received relatively low pay, and were not unionized. Extraordinary efforts went into the identification and location of the workers, including the use of commercial personal tracing firms.[5] TABLE 2 summarizes the results of this effort. Of the workers who were alive and could be located, over 90% of those living within the Augusta area participated in the medical program, and the majority of those workers who had dispersed to all parts of the country participated as well.

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TABLE 1. Comparative Characteristics of the Cohorts Notified in Demonstration Projects

		Comparative Characteristics of Cohorts							
Cohort	Location	Size/ Race/ Sex	Type of Work	Carcinogen	Target Cancer	Average Period of Exposure	Latency Period	Relative Risk	Medical Intervention Potential
Augusta Chemical Workers	Augusta, GA	1,150/70% black/male	Unskilled Industrial Nonuniion Low pay	Beta-naphthyl-amine	Bladder	1949–1974	18.6 yr	4–111	Good
Pattern makers	Nationwide	10,000 current, 2,000 former/all white/male	Skilled Industrial Craft Union High pay	Undetermined	Colon-rectal	Unknown	Unknown	2	Good
Flint Glass Workers	Port Allegany, PA	1,200/all white/male	Unskilled Industrial Union Medium pay	Asbestos	Lung	1964–1972	20 yr	10–53	Poor

TABLE 2. Augusta Project Notification and Participation Rates

Total no. in cohort	1,385		
No. assumed deceased before notification	272 (20%)		
No. with no address available	19 (1%)		
No. lost to follow-up[a]	245 (18%)		
No. assumed alive and notified	849 (61%)		
Geographic Distribution	In Area	Out of Area	Total
No. assumed to be notified	611	238	849
No. participating (% of those notified)	566 (93%)	138 (77%)	749 (88%)

[a] Notification letters returned as undeliverable.

Pattern Makers League of North America. In 1980, three independent epidemiologic studies were published that indicated that pattern and model makers may have a double risk of colon and rectal cancer.[6-8] These workers are almost entirely white men who are skilled, well-paid, and belong to a craft union. This cohort consisted of 10,000 current and 2,000 retired members of the Pattern Makers League of North America (PML). The PML represents members employed in 700 workplaces in 27 states and several Canadian provinces.

Port Allegany Asbestos Health Program. Approximately 1,200 workers, who are members of the Flint Glass Workers' Union in Port Allegany, Pennsylvania, have been determined to be at high risk of developing cancer associated with workplace exposure to asbestos at a glass and insulation products plant. In 1981, after lengthy discussions involving the Pittsburg Corning Corporation and the union, a nonprofit community program was set up with representations from the union, management, community groups, and medical providers, to provide notification, medical examinations, outreach, counseling, and education.[9] Because of the possibility of secondary exposure of family members to asbestos, the program has been extended to include workers' families.

These projects differ in major respects and provide a good cross-section of the medical, social, and political nature of the notification problem. The Augusta project was conducted in a situation of great social tension arising from ignorance, discrimination, and a history of neglect towards a serious health problem on the part of all responsible institutions.[10] The project employed a combination of "top-down" action on the part of a government agency (NIOSH) and grass-roots organizing of the afflicted workers and their social networks on the community level. This project was selected for inclusion as a pilot study because of the serious health risk to workers and because it represented a "worst case" scenario.

The Pattern Makers project represented a union-initiated response that was immediate once a problem became known. Although hesitancy about the program was expressed both by union representatives and by employers in some cases, on the whole its implementation was smooth. To some extent, this undoubtedly reflected that by 1980 our society had come a long way in recognizing the need to address occupational hazards with some degree of vigor and urgency. The Pattern

Makers project is unique in that it is the first multicenter intervention program in occupational medicine in the United States, and a great deal of valuable clinical research on early detection of colorectal cancer has been gained from it.[11]

The Port Allegany Asbestos Health Program celebrated its fifth anniversary last year and is an ongoing community health program. Although its genesis was a lengthy struggle between labor and management, once established this program became known as a "model of community cooperation" on a serious health problem.[12]

These projects demonstrated that notification and intervention programs for workers at high risk of occupational diseases can be conducted feasibly within the structures of community health and labor management relations in the United States. They also demonstrated that many different approaches can be used to achieve these ends. Consequently, policies directed at worker-notification and intervention should be flexible and build on the structures that already are in place.

OBJECTIONS TO WORKER-NOTIFICATION

In the course of hearings and debate on this issue within the U.S. Congress and the private sector, a number of objections to worker-notification and intervention programs have been raised. These objections, which can be found in the minority views in the House *Report*,[13] Senate *Report*,[14] as well as the debate on the floor of the House of Representatives,[15] are summarized under five headings which will be addressed:

1. There are no medical benefits for notified workers.
2. The legislation is a duplication of existing OSHA activities.
3. The legislation is too costly.
4. Notification promotes litigation.
5. Notification is damaging to workers.

No Medical Benefits

Too often the current bill in Congress has been thought of as a cancer bill, and lung cancer has been raised as a case in point to illustrate that medically nothing is gained by intervening. Apart from this damaging assessment of U.S. medicine in general and the 12% of the Gross National Product currently expended on medical care, the argument is tendentious and wrong in many respects as follows:

The legislation covers all occupational diseases, some with excellent survival potential and some with poor survival potential.

It is a utilitarian error to argue that medical benefits are the essential justification for this bill. The real justification resides in fundamental ethical and moral principles grounded in democracy: the right to self-determination, as reaffirmed in the Nuremburg code on medical research and the Helsinki declaration on informed consent, the precedent of notification in other areas of public health, such as victims of childhood thyroid irradiation therapy, and the principle of not withholding health information laid down after the Tuskegee syphilis natural experiments.[16]

This argument neglects the medical experience that even after exposure to lung insults such as asbestos, much can be done to reduce mortality from superimposed respiratory infections.[17] Additionally, on January 13, 1988, a professional consensus meeting at NIOSH concluded that intervention through early detection is valuable in lung cancer. This determination is being reaffirmed by officials of the National Cancer Institute.[18]

Bill Duplicates Existing OSHA Activities

It has been claimed that occupational high-risk notification and intervention is a duplication of activities carried out by the U.S. Department of Labor Occupational Safety and Health Administration (OSHA) under existing health standards and the Hazard Communications Standard. The deficiencies of this position were discussed extensively by Dr. Philip Landrigan, Professor of Pediatrics and Community Medicine, Mt. Sinai School of Medicine, New York, on February 24, 1987, and Dr. John Finklea, Professor of Preventive Medicine, University of Alabama, on May 15, 1986, in testimony before the Subcommittee on Labor of the Senate Committee on Labor and Human Resources. They have pointed out three areas not currently covered that would be covered by the new legislation:

Past exposures. In a dynamic economy many of the occupational diseases detected will relate to past exposures, given the long latency periods that may separate exposure from its clinical manifestation.

Former workers. Similarly, most workers will change occupations or places of work during their lifetimes.

Family members. Occupational household contact disease is not covered in any current programs despite the increasing recognition of this problem.

Legislation is Too Costly

Cost estimates as high as $53 billion have been attributed to this legislation. Debate on the floor of the House of Representatives suggested that it would threaten the economic competitiveness of the United States in world trade and have global economic consequences. These are gross overstatements. The fact is that the costs are already incurred, as is evident in the following simple calculation:

Assume the U.S. Department of Labor's estimate from 1980 that there are 1.88 million disabled workers in the United States.[19]

Although it is difficult to estimate the economic cost of occupational disability,[20] assume that the estimate of average costs from Johnson and Heler's study of 515 asbestos disability cases is representative of all occupational disability cases. They estimated a total cost to the worker and his or her family of $475,000 and of an additional $95,000 to society.[21] This means a total cost per case to the victim and society in excess of $500,000.

If both of these assumptions are correct, the total cost of occupational disability in the United States at present is approximately *one trillion dollars*.

The issue then is not the cost associated with notification and intervention, but rather who should pay these costs. Workers and their families are currently paying the bill. Not only that, but since these costs are being carried by the workers as individuals, these workers are paying a premium arising from the lack of an organized program of intervention. Consider the following estimates for the Pattern Makers program:

Cost of developing the program is $120,000, or $10 per worker for each of the 12,000 persons covered.

Cost of medical examination, including detailed occupational and medical history, physical examination, lung function testing and chest x-rays, urinalysis and blood work, stool hemoccult, and flexible sigmoidoscopic examination to 68 cm. The cost negotiated for this medical testing program ranged from $130 to $240 per worker examined, depending on location, number of workers involved, and the like. These low costs were obtained because they were negotiated for an organized group program. If these workers had arranged individually to obtain this same battery of exams and tests, the cost would easily have exceeded $1,000.

Another way of looking at this legislation, then, from a societal point of view, is that it would save significant amounts of money. An approach to calculating this has been developed by Ruttenberg and Powers.[22]

The Legislation is Litigious

It has been argued repeatedly that this legislation will open the floodgates for tort suits brought by workers against third parties and employers. Surprisingly, much of the hysteria about litigation has been caused by the U.S. Department of Justice, arguing that the U.S. Treasury may be vulnerable to a run against it by aggrieved workers who have been notified. This argument is disturbing for two reasons. First, the U.S. Constitution set up the Judiciary as a third branch of government to protect minorities against the excesses of majorities and to allow aggrieved individuals to seek redress. In this case, the government would effectively deny workers this constitutional right by withholding from them the information about their risk. Second, much of the concern about litigation has been expressed by referring to the demonstration projects presented here. The record from these three projects with regard to litigation is as follows:

In Augusta, 171 suits totaling $300 million in claims were filed. Of these, 120 were settled out of court for an estimated total of $500,000. The remaining suits were thrown out of court on statute of limitations grounds. Thus, for the 1,000 eligible, living workers in this group, the average recoupment through the courts was about $500. That is hardly a windfall.

In Port Allegany, only two suits are known to have been filed since September 1981, when the asbestos health program was started. Both of these cases were mesotheliomas.[23]

Among pattern makers, not a single suit is thought to have been pursued.

We have long held the position that tort litigation is a poor way to resolve social problems on a large scale and that a national system of prompt and equita-

ble compensation for occupational diseases is needed.[24] These projects suggest that litigation does not arise from the act of notifying workers, but rather from the failure to have notified them in the first place. Furthermore, the litigation is substantially a response to the lack of an organized system to deal with the special needs of workers at high risk.

Notification is Damaging to Workers

The final and most patronizing objection to worker notification is that workers cannot deal with this type of information. It is true that, in the short run, the act of notifying a high-risk cohort may create discriminatory responses against the workers, especially in employment and financial dealings. Instances of this were reported in the Augusta project. More dramatic, but similar, actions were experienced recently by HIV-positive individuals, much as lepers were treated in the past. Yet, based on carefully conducted psychosocial studies of the cohort in Augusta, no adverse affects were evident.[25]

This finding, which scientists were able to discern using sophisticated psychometric scales, was summed up by a woman in her late forties—the spouse of one of the Augusta chemical workers—who said one night during a community meeting in response to a question about whether the notification program was beneficial, "When you live from day to day, from hand to mouth, this is just one more in a series of life crises. We are just glad someone was willing to help us with one of them."

CONCLUSION

In the convoluted debate over the need for a national system of notification and intervention for workers with a high risk of disease it is easy to lose a sense of perspective, particularly when confronted with doomsday predictions on the grand scale that opponents of such a system present. Yet, tear away the fluff, and the issues present themselves clearly:

A large number of workers are known to be at high risk of disease because of past or present exposure to serious health hazards on the job. These individuals are identifiable and have rights as members of a democratic society to be informed about their risk.

The projects reported on herein demonstrate that notification and intervention can be provided feasibly within the structures of community health and labor management relations at minimum cost.

The suggestion that an organized program of notification and intervention is litigious simply is not supported by the facts as presented by these demonstration projects. Workers do not sue because of organized programs to address their needs; they sue as a measure of last resort in the absence of such programs.

The suggestion that an organized program of notification and intervention is economically not viable ignores the reality that the costs of occupational disability and premature death today are borne by the victims and society in the amount of approximately one trillion dollars. These costs are excessive in the

absence of an organized system because of the vast inefficiencies incurred by dealing with each case individually.

The High Risk Occupational Disease Notification and Intervention Act is an important step towards creating a national system for dealing with this problem. The legislation is not perfect, but then neither is our society. It is a start. It will give workers at risk a means to aid them in protecting their lives.

SUMMARY

There is currently a heated debate about whether the U.S. Congress should enact the High Risk Occupational Disease Notification and Prevention Act. This Act would set up an orderly system for identifying, notifying, and assisting workers at high risk of occupational disease. Significant underpinning for this legislation comes from three pilot projects conducted by the National Institute for Occupational Safety and Health and the Workers' Institute for Safety and Health. These projects demonstrate that notification and intervention for occupational high-risk groups can be implemented feasibly within the existing structures of community health and labor management relations. These projects also suggest that, contrary to the views of opponents of current legislation, it is the absence of systematic programs that leads to massive litigation and high costs. At present, these costs are borne by workers and society.

ACKNOWLEDGMENTS

This work was conducted collaboratively with Paul Schulte, Ph.D., of NIOSH, and Sandra Tillett and Kenneth Miller, M.D., at the Workers' Institute for Safety and Health. We are indebted to two preceding generations of intellect and action on this problem: Irving J. Selikoff, M.D., Professor Emeritus, Mount Sinai School of Medicine, New York, and Sheldon W. Samuels, Director of Health, Safety and the Environment, Industrial Union Department, AFL-CIO.

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